

## The Rodgers: Medical Debt Changed Their Lives

Rylin and David Rodgers were shocked at how quickly medical debt changed their lives. They had college educations, good jobs with health insurance, and comfortable savings before their children were born. Unaccustomed to asking for help, Rylin once went three days without eating as she sat by her son's hospital bed. "In retrospect I should have asked," she says, "but no one offered, either. I think we looked 'too good' to need help."

Rylin and David Rodgers were in good financial standing when they welcomed their first child, Matthew, into the world. Both teachers, they had a combined yearly income of \$60,000, owned their own home, and had zero consumer debt.

Six months later, even the ten dollars it cost to park at the hospital where Matthew was having surgery was well beyond the family's budget. "I would get up at 2:00 a.m. to go move the car," remembers Rylin. "There was no parking attendant there at that hour."

In just the first year of Matthew's life, his medical expenses would total over a million dollars.

Matthew and his sister Laura both have an unidentified type of mitochondrial disease, a degenerative and terminal illness. Rylin had to quit her job to care for them, which cut the family's income in half. Required by their health insurance to pay 20% of



Treating Laura and Matthew Rodgers for mitochondrial disease has led to hundreds of thousands of dollars in medical debt for the family.

all health care costs out-of-pocket, the couple took out three mortgages on their house. They have paid for some medical expenses with credit cards, including \$400 a week for laboratory tests and \$2,000 a month for prescription drugs.

*“Most people assume that a family like ours, because we have two college-educated parents, would have the resources they need to take care of their family’s medical conditions.”*

“Most people assume that a family like ours, because we have two college-educated parents, would have the resources they need to take care of their family’s medical conditions,” says Rylin.

In fact, social workers repeatedly told the family they wouldn’t qualify for assistance because their income was too high. “It wasn’t until Matthew was two and we were in major medical debt that we learned from another parent we’d been income-eligible the whole time for CSHCS.”

CSHCS, or Children’s Special Health Care Services, is Indiana’s Title V program. Once they enrolled, it helped the Rodgers pay for the children’s medical care for several years. When David received a pay raise, however, his income was pushed over 250% of the federal poverty level, and the family was no longer eligible.

By trimming their grocery budget to \$40 a week for the family of four, buying second-hand clothes, and foregoing non-essentials, the Rodgers are able to pay \$500 a month for the nutritional supplements that Rylin says are the only recommended treatment for the children’s condition. Neither Medicaid—which Matthew now receives, after ten years on a waiting list for a special waiver program—nor the family’s private insurance covers any part of the cost.

The Rodgers have had to make other difficult choices and adjustments. When they couldn’t afford the muscle biopsies required to diagnose the children’s condition, which were not covered by insurance, they chose to have just one child diagnosed. When wheelchair maintenance grew to thousands of dollars a year, they got the children scooters instead. And while four different subspecialists want to see Laura every month, she usually goes every three months. “I try to balance appropriate medical care with reality,” says Rylin.

One choice they didn’t make: “We were shocked by how many people advised us to divorce so we could get Medicaid.”

## Pathways to Financial Hardship for Families of Children and Youth with Special Health Care Needs (CYSHCN)

1. **Higher health care costs:** In just the first year of Matthew's life, the Rodgers were responsible for over \$200,000 in out-of-pocket medical costs. They paid for diagnostic tests they expected to cost \$20,000, but when Matthew developed serious medical complications the cost rose closer to \$100,000.
2. **Higher routine expenses:** The Rodgers pay \$500 a month for over-the-counter nutritional supplements for Matthew and Laura.
3. **Loss of employment income:** Rylin had to quit her teaching job to care for the children, which cut the family's annual income from \$60,000 to \$30,000. David has considered changing careers to something more lucrative, but he stays in teaching because of the medical insurance.

### Breaking the Link to Financial Hardship for CYSHCN

1. Well-educated and middle-class, the Rodgers were repeatedly told they wouldn't qualify for public assistance. [Benefits counseling](#) would have helped them to enroll Matthew in Title V services right away, instead of accruing thousands of dollars in medical debt before learning about the program from another parent when their son was two.
2. Matthew was on a waiting list for ten years before he could receive Medicaid benefits; Laura is still waiting. A [Medicaid buy-in program](#) like the one that is part of the [Family Opportunity Act](#) would have allowed the family to enroll the children without a waiting list, paying a [premium](#) determined by their income.
3. Some states have passed specific [mandated benefits](#) that require health insurers to pay for special services like nutritional supplements. If Indiana were one of those states, the Rodgers family would be able to use their private insurance to pay for Matthew and Laura's extra nutritional needs.

---

This story first appeared in [Breaking the Link to Between Children's Special Health Care Needs and Financial Hardship](#) in February, 2009.

### The Rodgers at White House meeting in July 2011

On July 7, 2011 three families of children with special health care needs, including Laura and Rylin Rodgers, met with senior officials at the White House to talk about the importance of Medicaid in their lives. Read [Laura's blog posting](#) about this meeting and visit the [Catalyst Center's blog description](#) of the White House meeting.

## About the Catalyst Center

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs is a national center funded by the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, and is located at the Boston University School of Public Health. The Catalyst Center provides support to the efforts of stakeholders at the federal, state, and local levels in assuring adequate health insurance coverage and financing to meet the diverse needs of children and youth with special health care needs and their families.

## Contact Information

Meg Comeau, Project Director  
The Catalyst Center  
Boston University School of Public Health  
Health & Disability Working Group  
715 Albany St.  
Boston, MA 02118  
Tel: 617-638-1936  
Fax: 617-638-1931  
Web: <http://www.catalystctr.org>  
E-mail: [mcomeau@bu.edu](mailto:mcomeau@bu.edu)

*The Rodgers: Medical Debt Changed Their Lives*, a publication of the Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs, February, 2009. The Catalyst Center is funded under cooperative agreement #U41MC13618 from the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. Lynda Honberg, MHSA, MCHB/HRSA Project Officer. The contents of this work are solely the responsibility of the authors and do not necessarily represent the views of the funding agencies or the U.S. government.

